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What Do Newly Diagnosed Cancer Patients Discuss with Survivors?

Kimberly Dasch, M.A.¹ and Jeff Kendall, Psy.D.²

Abstract

The Cancer Companion Program at the Helen F. Graham Cancer Center is a peer-to-peer telephone-based program that connects a newly diagnosed cancer patient with a previous cancer patient with the same diagnosis. Similar peer support and telephone-based programs have been studied, and many benefits have been found in previous studies. As such, this study focuses not on program efficacy, but rather aims to understand the topics that newly diagnosed cancer patients discuss with cancer survivors. Participants in this study were 41 newly-diagnosed cancer patients who had requested to be matched with a volunteer cancer companion. Content analysis of the phone call logs demonstrated that patients discussed treatment-related, psychological, and day-to-day concerns. These results are discussed in terms of educating physicians, nurses, and psychosocial cancer care practitioners about the issues which are most important to newly diagnosed cancer patients.

Key Words: Psychosocial Cancer Care; Peer Support; Phone-based Interventions

INTRODUCTION

The number of psychosocial programs for cancer patients is increasing. With the increase in programs, more diversity of program type is available. With cancer patients, face-to-face counseling and group-based interventions are not always a good fit because many cancer patients are reluctant to seek mental health counseling.¹ Therefore, telephone-based interventions can be used to provide needed psychosocial support to new cancer patients, in a flexible, private manner, without transportation or scheduling issues that may arise with other interventions.²

The Cancer Companion Program at the Helen F. Graham Cancer Center is a peer-to-peer telephone-based program that offers support to newly diagnosed patients. Cancer companions are cancer survivor volunteers who have progressed at least six months beyond their primary active treatment(s). Volunteers receive training to provide telephone support to newly diagnosed patients and are then matched with patients with a similar diagnosis.

Similar peer support programs have been studied, and many benefits have been reported. For cancer patients, peer support programs have demonstrated benefits of increased sense of reassurance and encouragement,³ being better informed about the cancer experience,³ having better relationships with their physicians,³ and obtaining higher levels of social support.⁴ In addition, cancer patients have reported that talking with a cancer survivor allows for the

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normalization of the treatment experience and promotion of the belief that life can return to normal following treatment.⁵

Other investigations have focused on the experience of the volunteer in peer support programs and have shown that survivors are more helpful, supportive, empathetic, and less critical, than spouses or partners.⁶ In addition, research has found that having cancer patients as volunteers not only benefits the people they

are trying to help, but also the cancer survivor themselves. Personal growth, improved communication skills, and adapting to their own personal cancer experience are all reported benefits for volunteers.⁷

As the efficacy of peer-to-peer and telephone-based interventions have already been established by previous studies, the efficacy of the program is not the focus of the current study. Rather, this study aims to better understand

Table 1. Content Analyses Categories

TOPIC	EXAMPLE
Barriers	"Wants to do programs but does not want to impose on her family anymore with lots of doctor appointments"
Care/Services at HFGCC	"The companion program and amount of available resources at HFGCC"
Chemotherapy/Radiation	"Finished her radiation therapy, went well, doesn't need chemotherapy"
Communication with Physician	"Hesitant to bother her doctors, but getting more aggressive when necessary"
Coping	"Told her it was okay to be selfish now and only take care of herself, have someone screen calls"
Day-to-Day Life	"First day back to work, stayed all day, coworkers impressed, impressed volunteer remembered"
Diagnosis	" Had CAT scan, diagnosed with small cell cancer"
Family/Friends	"Children and how it will affect them"
Hair Loss	"Hair loss – where to find wigs and hats, both have small heads, shop in kid's for hats"
Information	"Patient inquisitive about volunteer's case – surgery, recovery period, effects of follow-up therapy"
Negative Emotions	"Since diagnosis, everything has exploded, feeling overwhelmed and devastated"
Nutrition	"Lost appetite, discussed importance of nutrition"
Pain	"Concerned not healing well from surgery, still experiencing pain and pain pills make her itch"
Positive Emotions	"Well-adjusted and positive, outlook on chemo session is that it's time to catch up on reading"
Side Effects	"Nausea, wanted to know if volunteer had suffered from sickness, volunteer had not"
Surgery	"Making a decision on whether to have more surgery to put in an implant or leave things as are"
Test Results/Prognosis	"Physician called today with CAT Scan results – results were good"

the topics that newly diagnosed cancer patients want to discuss with cancer survivors. These data can help guide and inform the data provided by physicians, nurses, and psychosocial cancer care practitioners to newly diagnosed cancer patients.

METHOD

Participants

Participants in this study were 41 newly-diagnosed cancer patients who had requested to be matched with a volunteer cancer companion. Prior to being matched with a volunteer, newly diagnosed patients interested in the program completed an initial information sheet, indicating their name and phone number, good time to call, gender, cancer type, and age. This information was then used to match the patients with a similar volunteer, as well as to determine the demographics of the current analysis.

Content Analysis

During each phone call, the volunteer completed a log of the topics discussed with the newly diagnosed patient. A content analysis was conducted on phone call logs, with the two authors each independently assigning each log entry a topic category. Seventeen topic categories were identified. Any disagreements in category assignment were discussed and resolved between the authors. Table 1 contains the content analysis topic categories and an example of a volunteer's phone log entry for each topic.

RESULTS

Population Characteristics

Forty-one patient call logs were analyzed. Out of the 41 patients called, 30 (73.2%) were female and 11 (26.8%) were male. With respect to cancer type, 14 (34.1%) were breast cancer patients, 9 (22%) were lung cancer patients, 9 (22%) were head and neck cancer patients, 4 (9.8%) were genitourinary cancer patients, 2 (4.9%) were ovarian patients, and 1 each (2.4%) were a pancreatic cancer patient, a rectal cancer patient, and a brain cancer patient. Patients

were a diversity of ages as well, with 4 (9.8%) between 31-40 years old, 6 (14.6%) between 41-50 years old, 11 between 51-60 years old (26.8%), 9 (22%) between 61 and 70 years old, 1 (2.4%) between 71-80 years old, 4 (9.8%) between 81 and 90, and 6 (14.6%) were of unknown age.

Topics Discussed Between Cancer Patients and Survivors

During the content analysis process, 17 commonly discussed topics were found. The percentage of phone calls where each of the 17 topics were discussed is in Table 2.

Table 2. Percentage of Phone Calls Where Topics Were Discussed

TOPIC DISCUSSED	PERCENTAGE OF PHONE CALLS
Side Effects	56.1%
Family/Friends	36.6%
Positive Emotions	34.1%
Chemotherapy/Radiation	31.7%
Negative Emotions	29.3%
Coping	26.8%
Surgery	24.4%
Diagnosis	24.4%
Nutrition	24.4%
Day-to-Day Life	24.4%
Communication with Physician	22.0%
Information	22.0%
Care/Services at HFGCC	19.5%
Test Results/Prognosis	19.5%
Pain	14.6%
Hair Loss	12.2%
Barriers	7.3%

DISCUSSION

Previous research had determined that peer support programs have psychosocial benefits to both the newly diagnosed patient and the volunteer. In addition, previous research determined that telephone contact can be an effective way of delivering this support. Consequently, the focus of the current study was not on program efficacy, but rather on what topics were discussed between the patient and the cancer survivor volunteer. A better understanding of the topics that newly diagnosed patients discuss can inform both the in-person communication and the print educational materials of physicians, nurses, and psychosocial cancer care practitioners.

The most frequently discussed topic was treatment side effects with 56.1% of the calls spending some time on this topic. This result is somewhat interesting in that approximately only one out of every two calls discussed treatment related side-effects. Anecdotal experience by all types of oncologic specialists may have predicted that topic to be more prevalent. This result does validate the amount of time oncologic specialists spend educating patients about the side effects of treatment both in person and with print materials. This result raises the hypothesis that the amount of time spent educating patients about treatment side-effects in this sample is effective enough to reduce the number of patients who need to further discuss these issues. Future investigations are required to examine this hypothesis.

The second and third most common topics discussed are the impact of cancer on family/friends and efforts to remain affectively positive during the course of treatment. Although it is not surprising that social and emotional issues are important to cancer patients at diagnosis, it is interesting that these issues are discussed more frequently than the medical issues of chemotherapy, radiotherapy, surgery, or pain. These results emphasize that today's oncology patient's are looking for support in both medical and social/emotional domains. This hypothesis is further supported in that six of the top 10

topics discussed fall within psychosocial domains rather than purely medical domains. These data also provide some support for the conclusion that cancer patients take into account multiple domains when determining their level of satisfaction with their cancer care.⁸

The primary limitation of this study is the small sample size. Given the small sample size it cannot be ruled out that the ranking of the topics would change with a more representative sample. Another limitation of these data is the possibility of a self-selection bias in our sample. It is not unlikely that the subset of newly diagnosed cancer patients who would request to speak with a volunteer may require more psychosocial care than those who do not ask for a volunteer. A larger randomized sample is necessary to determine if these findings are representative of the newly diagnosed population or if those that seek out peer to peer assistance are in greater need of emotional and social support.

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